



PSORIASIS: COPING WITH SOCIAL STIGMA

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ABSTRACT

A qualitative study of individuals living with psoriasis has been conducted in Tuaran District, Sabah. It aimed in exploring the experience of being stigmatized, describing the coping strategies used and its effectiveness in dealing with social stigma. With in-depth interview to nine participants in this qualitative research, it is found that stigmatization was triggered by the visibility of the disease – marked by visibility; to cope with this stigmatization, they tended to hide and conceal it - the act of concealment; they tried to avoid the public and preferred being alone; developed feeling of anger and self-blaming; telling self “I don’t care”; and find source of support. With the coping strategies, these give them the feelings of belonging; making adjustment and changes in self. Through this study, it suggests nurses to imply holistic and spiritual nursing in caring for individuals with psoriasis. Whilst for the society, this study creates awareness and understanding in the social stigma that have experienced by individuals with psoriasis, thus bringing them back to the society.

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I also want to thank my mother as she is my inspirational in this study. Therefore, this study is dedicated to my mother for her bravery in fighting with psoriasis for almost 20 years.

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KEY TO TRANSCRIPTIONS

<i>Italic</i>	Participants' interview data which had been translated from “Bahasa Malaysia” (Malaysia Language) and “Bahasa Dusun” (Local Sabahan Language) to English.
Names	All the participants' names mentioned in this study are pseudonyms. This is to maintain confidentiality of participants
..//..	Part of the materials from the interview excerpts are deleted.
...	The participant paused during interview.

(Adopted from Zabidah, 2009)

SECTION 1

INTRODUCTION

This is a study of individuals with psoriasis using qualitative approach regarding social stigma. Their stigmatization experiences, coping strategies used and it's effectiveness in dealing with social stigma were explored in this study.

Background of the Study

Psoriasis is described as a common but complex disease. The skin presented with red scaly patches which cause by the rapid proliferation of the skin. The distribution of the disease varies. It can affect people at any age. Although psoriasis had been long known to mankind, there is still no cure. In Malaysia, the prevalence of psoriasis ranges from 4% to 5.5% (Cimmino, 2007). Both Camisa (1994) and Dermatological Society of Malaysia (2008) characterized psoriasis as a “*non-life-threatening*” disease but as a disease that “*ruins*” lives. As stated by Roenigk and Maibach (1991),

contagion, filth and leprosy were associated with psoriasis for centuries. Furthermore, impairment of social and occupational functioning can occur to a significant degree as the presence of psoriasis in areas of high visibility such as the face and hands. According to Gilbert and Miles (2002) in “*Body Shame*”, physical appearance plays a powerful role in social relationships. The feeling of shame towards self-appearance and perception of others view their appearance negatively can be vulnerable to impoverished social relationships and to a range of psychological difficulties. Therefore, individuals having psoriasis experienced uneven social and psychological penalties. To understand this phenomenon, this study explored stigmatization experienced by individuals with psoriasis, their coping strategies and it’s effectiveness in dealing with social stigma.

Statement of the problem

This study focuses on the stigmatization of psoriasis. The gap of knowledge that have been identified for nursing practice are the coping strategies used and the effectiveness of coping strategies in dealing with social stigma. Individuals with psoriasis are often being masked by their disease. International Federation of Psoriasis Association (2007) recognized social stigma as a “hidden disease” in individuals with psoriasis. Therefore, psoriasis is not a disease that involves the physical aspect of the person, but also the psychosocial aspect. Shives (2008) described holistic nursing as caring the person as whole which take account on the

person's body, mind and soul. Hence, holistic nursing is needed in caring for individuals with psoriasis.

Psoriasis is a skin condition which had been misunderstood by the society over the centuries due to its presentation resembles similarity with other disease (Hong, Koo & Koo, 2008; Gittings, 2005; Krueger, Koo, Lebwohl, Menter & Stren, 1998; Bart, 1992; Roenigk, et al.). Individual with psoriasis are discriminated by their skin appearance. According to Griffin (2009), this had caused them to be emotionally stress such as anxious, worry, and fear about people reaction towards their skin condition and society view about physical appearance. Patient with psoriasis are being stigmatize, discriminate because of their physical appearance. Their coping strategies will determine their self esteem, functionality and socializing.

In Malaysia, several studies had been conducted regarding psoriasis. One of the earliest studies done was in 1980 by Adam in the prevalence of psoriasis and this was further broadened by Siow, Mohd Safdar, Chong and Chua (2004) in their studies of the sociodemography of psoriasis. The establishment of Malaysian Psoriasis Registry in 1998 had provided useful data on various aspect of psoriasis (Chang, Gangaram, & Hussein, 2008). Most of the studies mainly focusing on managing the skin disease which included the treatment that had been provided in the health care services, the assessment of the disease in terms of diagnosing and determining the efficacy of

treatment (Fadzil, Ihtatho, Affandi, & Hussein, 2009; Hashim, Rahman, Jarmin, & Mohd Nasir Taib, 2006; Asmah, 1998). A study conducted by Kim et al. (1999) was assessing the patients' knowledge of psoriasis. Furthermore, the local media in Malaysia had addressed the disease to the public. Despite the growing awareness of psoriasis in Malaysia, there was still lack of study concerning the social and psychological aspects of psoriasis being addressed.

During my Year 1 attachment at Serian Hospital in April to May 2007, I had the opportunity to observe and nurse patient with psoriasis. People often isolate and fear to touch them. This was due to the appearance of their skin which similar to contagious skin diseases. There were also discussion with colleagues about their views, attitude and reaction toward psoriasis or any other skin disease. The skin appearance of the individuals with psoriasis and the disease as being contagious were the most common topic that being discussed. Moreover, my mother is one of the individuals who have suffering from psoriasis. This makes me even more eager to explore the meaning of stigma in individuals with psoriasis, their coping strategies and as well as it's effectiveness in dealing with social stigma.

Research Questions

The research questions for this study are:

- a. What are the experiences of stigmatization by individuals with psoriasis?
- b. What are the coping strategies used by the individuals with psoriasis to cope with social stigma?
- c. How do the coping strategies help individuals with psoriasis?

Research objectives

The general objective of the research is to explore the coping strategies used by individuals with psoriasis in dealing with social stigma. The research will aim to achieve the following specific objectives:

- a. To explore the stigmatization experienced by individuals with psoriasis.
- b. To describe the coping strategies used by the individuals with psoriasis.
- c. To discuss the effectiveness of coping strategies to deal with social stigma.

Significance of the Study

This study will be a significant endeavour in decreasing the stigmatization of psoriasis and alternative ways in coping with social stigma. The study will also be helpful for the health care team as guide in rendering care for clients with psoriasis who face with social stigma. This will aid them in identifying possible problems that may occur that caused by stigmatization feeling and be able to make a plan of care for the patient and help them to enhance their role as health care providers in meeting the psychosocial needs of the clients. Through this study, the society will able to increase

their knowledge and awareness about psoriasis, thus at the same time to reduce the stigmatization of psoriasis among the society.

Moreover, this study will be an important contribution to a body of research concerning psoriasis, coping strategies and social stigma. The future researchers can gain pertinent information about the nature of the client's condition and use the research as a new knowledge in providing health care and meeting the needs of a client with the same condition.

Operational Definition of Terms

The operational definitions of terms commonly used in this research are *Psoriasis*, *Coping Strategies*, *Social Stigma* and *Stigmatization*.

Psoriasis:

Dorland (2007) defined psoriasis as “*a chronic, hereditary, recurrent dermatosis marked by discrete vivid red macules, papules, or plaques covered with silvery lamellated scales.*” However, in my study, psoriasis refers to the chronic skin disease whereby the areas that affected cause body disfigurement to the sufferer.

Coping strategies:

According to Taylor (1998), “*coping strategies refer to the specific efforts, both behavioural and psychological, that people employ to master, tolerate, reduce, or*

minimize stressful events.” Therefore, for my operational definition of coping strategies refer to the specific efforts behavioural and psychological, those individuals with psoriasis employ to master, tolerate, reduce, or minimize social stigma.

Social stigma:

Bhusahn (2003) defined social stigma as “*an undesirable differentness of an individual that disqualifies him from full social acceptance.*” Based on my study, social stigma operates as individuals with psoriasis experience a severe social disapproval.

Stigmatization

Stigmatization refers to “*the act of labelling a person as of lesser social standing, transforming their character and social standing in negative ways*” (White, 2006). In my study, stigmatization operates as the act of labelling individuals with psoriasis, transforming their character and social standing in negative ways.

SECTION 2

REVIEW OF LITERATURE

For my initial step in embarking this study, I had selected several literatures which comprised of quantitative and/or qualitative method. Although my study methodology is based on qualitative research method, by reviewing both of this study methods helped broadened my scope of study. The core of my study is the coping strategies used by individual with psoriasis in dealing with social stigma. Therefore, through this review, I have identified the stigmatization experiences by individuals with psoriasis, coping strategies used by them and it's effectiveness in dealing with social stigma.

Stigma

Psoriasis has given a deep impact to the sufferers in terms of physical, emotional and social functioning. The presentation of the disease itself becomes the limiting factor in social functioning which associated with stigmatization. In the qualitative study

conducted by Uttjek, Nygren, Stenberg and Dufåker (2007), the trigger for stigmatization towards individuals with psoriasis is when the disease was visible to the public. They were being described as having contagious skin disease such as “leprosy” or “syphilis” as their skin seen by the public. One of the main findings in the study by Wahl, Gjengedal and Hanested (2002), *“the feeling of being stared at”* was inflicted due to the visibility of psoriasis. Studies show that individuals who suffered psoriasis in younger age experienced greater stigmatization than those developed later in life (Uttjek et al., 2007; Perrot, Murray, Lowe & Mathieson, 2000; Krueger et al., 2001).

Rejection

Social rejection in public places was one of the stigmatization experienced by individual with psoriasis which they were *“being asked to leave”* or *“problem with receiving equal service or treatment”* (Hong et al., 2008; Krueger et al., 2001; Ginsburg & Link, 1993). Furthermore, individuals with psoriasis experience stigmatization due to the misconception the disease to be contagious or confusion with other diseases such as leprosy and syphilis (Hong et al., 2008; Uttjek et al., 2007; Gittings, 2005; Krueger et al. 2001; Bart, 1992). As a result, *“feelings of being flawed”*, *“secretiveness”* and *“sensitivity to opinions of others”* were perceived in individuals with psoriasis (Bart, 1992). In addition, individuals with psoriasis were

“being self conscious” toward themselves in terms of clothing and appearance (Gittings, 2005).

Coping Strategies

Studies have shown that individuals with psoriasis have varies coping strategies to deal with stigmatization. To counteract the stigmatization towards individuals with psoriasis, they hide or conceal their disease from the public (Uttjek et al., 2007; Gittings, 2005; Wahl et al., 2002; Leary, Rapp, Herbst, Exum & Feldman, 1998). Studies show that individuals with psoriasis tend to avoid themselves in activities that would anticipate stigmatization which usually lead to isolation (Uttjek et al., 2007; Silva, Müller & Bonamigo, 2006; Gittings, 2005; Wahl et al., 2002). Gittings (2005) also found that individual with psoriasis developed defense mechanism such being standoffish and unapproachable. Self-blaming occurred as the result of sense of hopelessness, wishful thinking and being fatalistic (Hernández-Fernaund, Hernández, Ruiz, & Ruiz, 2009; Gittings, 2005; Wahl, et al., 1999). Their coping mechanism also involve significant others which describe in the finding under social support (Uttjek et al., 2007; Silva et al., 2006; Gittings, 2005; Ginsburg & Link, 1993). After long term of period having psoriasis, they begin adjust themselves with the disease (Uttjek et al., 2007; Gittings, 2005). Both Gittings (2005) and Bart (1992) found that individuals with psoriasis suggested educating the public about psoriasis to help in dealing with stigmatization of psoriasis.

Effectiveness of Coping Strategies

According to Wahl, Hanestad, Wiklund and Moum (1999), the use of emotive coping had significant relationship with negative outcome in terms of disability and mental health. This was further support by Wahl, Mørk, Hanestad and Helland (2006), coping strategies such as “*confrontational*” and “*optimistic*” result in better quality of life while “*evasive*” and “*emotional*” in opposite result. However, these results were based on quantitative study. Therefore, it gives little explanation regarding the effectiveness of those coping strategies.

Through the literatures, it is found that the stigmatization experiences and coping strategies among individuals with psoriasis is yet not being explored fully especially in Malaysia where we have diverse and multicultural society. Moreover, there are still limited studies regarding effectiveness in coping social stigma especially in qualitative study.

SECTION 3

METHODOLOGY AND METHOD

Qualitative Research Method

In this study, I chose qualitative research method in exploring the coping strategies used by individuals with psoriasis in dealing with the social stigma. Qualitative research method is most appropriate for my study, as this approach helped me to understand the nature of human in terms of their experiences. This research method allowed me to “*describe life experiences*” by individuals with psoriasis in coping social stigma and “*give them meaning*” through systematic, interactive and subjective approach (Crookes & Davies, 1998). As this type of research is “*orientated to understand human nature*” (Basset, 2004), this characteristic allowed me to be involved in the participants actual experiences. In qualitative research, the participant was “*viewed as meaning markers*” throughout the process (Gubrium & Holstein, 2001). Therefore, the findings were presented based on the participants’ own word and further enhance the uniqueness of each individuals’ experiences.

Ethical Consideration

The ethical approval for this study was obtained from Ethical Review Board Committee, Faculty of Medical and Health Sciences, UNIMAS by submitting the research proposal and letter (see Appendix A). For the participants, the approval letter was shown to them (see Appendix B) and explanation regarding the study had been given in verbal and written manner. A copy of the written consent had been handed to the participants (see Appendix C).

Sampling Method

In this study, I used snowballing method in selecting my participants which constituted of individuals who had been diagnosed with psoriasis. Snowball sampling is “a nonprobability sampling method” where “each person interviewed maybe ask to suggest additional people for interviewing” (Babbie, 2008). The participants were gathered through the help of my relative that also having psoriasis. She introduced me to the five participants and the interviews for the participant were conducted individually in their own choice of venue. Then I was again being introduced to another two more participants. To reach for saturation of data, I was able to have three more participants through one the participants. However, one of the participants was not contactable. Therefore, the total participants in this study were nine. The study included the individual who had been diagnosed with psoriasis at least a year

and excluded individual with other skin disease similar to psoriasis or associated with other disease.

The Participants

There were nine participants who volunteered in this study. This study constituted of one female and eight males participants. The age of the participants ranges from 40 to 54 years old. Most of them had psoriasis for over 20 years. The ethnicity of participants was Kadazan/Dusun, a local ethnic in Sabah. All of them are married. For their educational background, one participant received secondary school education, four participants were diploma holder and another four were master degree holder. In terms of occupation, one worked as a mechanic and six of them were government servants. Another two were already pension but one was running a workshop. All of them were diagnosed with psoriasis by dermatologist at Queen Elizabeth Hospital, Kota Kinabalu, Sabah.

Question Guidelines

The question guidelines use in the study was semi-structured interview (refer to Appendix D). Semi-structured interview allow the researcher to obtain information from the participants by following the guided questions that had been structured without forgetting the question. It also allows the participants the freedom to

elaborate the questions as it use open-ended questions (Crookes & Davies, 1998). This technique was “*use when the researcher knows most the questions to ask but can not predict the answer*” (Morse & Field, 1995). The question guidelines was divided into five sections: A) Personal data, B) Understanding of the disease, C) Stigmatization experience, D) Coping strategies and E) Effectiveness of coping strategies. These question guidelines were developed under the support and guidance of my supervisor. I had conducted pilot studies with three participants for my question guidelines in *Bahasa Malaysia*. They were my colleague, my friend which currently taking her Bachelor Degree in Education at UMS and my mother. Based on these pilot studies, it helped me to become familiar with the interview sessions. Thus, I became more confident in handling the actual interview. After conducting the pilot studies, I also found out that certain questions in the guidelines can not be understood and prone to be misinterpreted after been translated from English Language to *Bahasa Malaysia*. Therefore, I improved the style of probing and the way I conveyed the questions in *Bahasa Malaysia*.

Data Collection

The interview was done during my one week mid-semester break in September 2009 and five weeks semester break in Mid November to third week of December 2009. The interview session was done face-to-face and the participants were individually interviewed at the place of their choice. The interview lasted about 40 to 60 minutes

per session. Before starting the interview, explanation for the purpose of the interview was given. I addressed the terms of confidentiality and explained the format of the interview to the participants. I also had provided my contact information. Lastly I asked if there have any inquiries regarding the study. After clarifying their doubt regarding the interview, I proceed to the interview session. I started by asking the participants some casual questions such as “how are you today?” and “what you had been doing last weekend?” This was as an initial step in building rapport with the participants. Yeschke (2003) explained that rapport is essential in interview to build mutual confidence and trust between the interviewer and interviewee. After both of us felt comfortable in conversing to each other, then I began to asked question regarding the topic. I allowed the participants to express themselves after each question was asked and listening attentively to their experience. However, when the participants answer seem to be misleading; I tried to lead them back to the topic by rephrasing the last sentence which was relevant to the topic. To avoid any misinterpretation of data, I summarised each of their explanation. For the last three participants, they were interviewed through telephone because of the geographical problem and time constraint. The study was conducted at Tuaran District, Sabah. Thus, as a student status in UNIMAS, I can only fly back to Sabah during the mid semester or semester break. Furthermore, not all the participants were available during that time due to work-related reasons. The interview session was recorded with an audio recorder in MP3 format. They had been assured that the data recorded will only be access by me and my supervisor if she requires so. All this data were kept in laptop which

accessible only to me. After finishing my study all the audio and written data will erase and eliminated.

Data Analysis

The data analysis of this study was done manually. I chose to analyse the data manually as I wanted to preserve the meaning of the data in their context. Furthermore, the software that was available for qualitative data analysis only applicable in English Language. Translation for the whole transcription was not possible due to some words could not be translated directly to English Language. This will cause the loss of significant data in the interview. The recorded interview was transcribed by me with the support and guidance from my supervisor. Translation of the transcription was done to the corresponding English words. Some of words will be retained in either “Bahasa Malaysia” or “Bahasa Dusun/Kadazan” if translation was not possible or applicable. I used dictionary and thesaurus to assist me in the process of translating.

For analysing the data, I used wholistic or sententious approach and selective or highlighting approach which was described by Van Manen (1990, cited in Zabidah, 2001). Therefore, these two approaches guided me by interpreting the descriptions and experiences of individuals with psoriasis coping with social stigma as whole and then selecting the essential data which addressing to the phenomenon.